Living with Breast Cancer: Experiences and Perceptions of Women in Georgia

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Abstract

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Aim: The purpose of this study is to improve understanding of the knowledge, beliefs and attitudes of women in Georgia living with breast cancer so as to identify barriers and facilitators to breast health care.

Background: Breast cancer is a leading cause of death among women in Georgia and the leading cause of death among women of reproductive age (Serbanescu, 2009). The 2008 age-adjusted incidence and mortality rates for breast cancer among all women are 38.5 per 100,000 women and 19.5 per 100,000 women respectively (GLOBOCAN, 2008). Despite efforts to increase awareness of breast cancer and improve access to screening, there is a lack of information, data, and understanding of the challenges women face, how women are seeking care, interacting with the public health system and making decisions about breast health care.

Method: This qualitative study uses thematic analysis to examine narratives from 19 in-depth semi-structured interviews with women diagnosed with breast cancer and one focus group discussion with 12 women. All data were collected in July 2011.

Findings: Analysis of the data revealed three major factors influencing women's experiences, perceptions and breast health care seeking behavior in Georgia: beliefs, awareness and resources. These factors are used as categories to illustrate both barriers to detection and treatment as well as facilitators for survival. Barriers to detection and treatment were expressed in terms of fear, denial and disbelief while facilitators for survival were expressed in terms of faith, dignity and agency.

Conclusion: As Georgia expands programs providing free breast cancer screening across the country, additional efforts should be made to educate women about risk factors for breast cancer and the benefits of screening. A majority of breast cancer survivors who participated in this study show a strong interest in educating women about the illness and would benefit from advocacy training to advance survivorship awareness and address barriers to care.

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LIST OF ACRONYMS AND ABBREVIATIONS

BSE	Breast Self-Exam
CDC	U.S. Centers for Disease Control and Prevention
NCDC	Georgian National Center for Disease Control and Public Health
NCC	National Cancer Center
NSC	National Screening Center
RAMOS	Reproductive Age Mortality Study
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
WHO	World Health Organization

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DEDICATION

To the women of Georgia who have faced breast cancer and so many other challenges yet continue to look forward with hope and faith. May your stories inspire other women to share their experiences to end the silent suffering and to encourage increased support for women's health in Georgia.

INTRODUCTION

Cancer is a leading cause of mortality worldwide, responsible for 7.6 million deaths or roughly 13% of all deaths in 2008, 70% of which occurred in low- and middle-income countries. This is predicted to rise to 13.1 million deaths annually by 2030 (WHO, 2012). Among women, breast cancer is the leading form of disease, accounting for 16% of all female cancers (WHO, 2008). As a result of this rise, more women are dying today worldwide from breast and cervical cancer than maternal mortality (Forouzanfar, 2011).

Incidence and mortality rates vary greatly by region, but while mortality has declined in Western Europe since 1980, it continues to climb in some Central and East European countries, including Georgia (Autier, 2010; Forouzanfar, 2011). In 2008, the age-adjusted incidence rate for breast cancer for all women in Georgia was 38.5 per 100,000 women; the mortality rate was 19.5 per 100,000 women (GLOBOCAN, 2008). According to data from the Georgian National Cancer Center, in 2010, the most recent year for which data is available, 1221 women were diagnosed with breast cancer in Georgia and 598 women died from the disease resulting in a 0.5 mortality-to-incidence ratio, meaning there are approximately 5 deaths for every 10 newly diagnosed cases, compared to a ratio of 0.2 in the United States (Georgian National Cancer Registry, 2010; SEER, 2012; Harford, 2011). Breast cancer is a leading cause of death among women in Georgia and the leading single cause of death among women of reproductive age (14-49) at 11.3 per 100,000 (Serbanescu, 2009). The five year survival rate for this age group is 18.9% compared to 89% in the United States (SEER, 2012). In neighboring Russia and Ukraine 5-year survival rates were 50-54% between 1994-2004 and 80% in Western Europe for the same period (Hirte, 2002). Higher case fatality rates in low- and middle-income countries have been attributed to, among other factors, a lack of awareness regarding the benefits of detection and treatment and late stage diagnosis (Shulman, 2010; Serbanescu, 2009).

Efforts have been made to increase awareness about breast health and improve access to breast cancer screening in Georgia, yet little is known about how women in Georgia view and experience breast cancer from diagnosis through treatment and beyond. There is a need to develop a better understanding of how women view breast health and their experience living with breast cancer to identify the barriers and facilitators to screening, treatment and survivorship as well as inform policies and practices in health care delivery.

Background

Georgia is a mountainous country at the crossroads of Europe and Asia with a population of 4.6 million; 1.48 million of whom reside in the capital Tbilisi. The country is currently facing a negative population growth rate due to outmigration and declining birth rates. By 2000, total fertility had fallen to 1.07, below replacement level (Collins, 2003). Just over 50% of the population is urban; however, this too is declining as a result of migration. Literacy remains high at 100% and mean years of education is 12.1 for adults, yet the country ranks below the regional average on the Human Development Index (Klugman, 2011). Economic hardship is widespread and unemployment is estimated at 40% in Tbilisi and as high as 60% nationally.

Political instability, armed conflict and economic collapse have overwhelmed Georgia since independence, disrupting public services and impeding efforts to address the struggling health care system. By 1998, Georgia's total expenditures on health care as a percentage of GDP dropped to 0.6%, making it 47th out of 47 countries ranked in the WHO European Region (including all of the former Soviet Union) (Gamkrelidze, 2002). The health care system has undergone multiple reform efforts in the transition from a public to a private health care delivery system with a new emerging insurance market, but efforts have been incomplete and hindered by the lack of a unified approach (Westoff, 2008; Collins, 2003; UNDP, 2008). Still, little is known about how Georgians manage and experience health care in the midst of these changes.

In 2007, the Georgian National Center for Disease Control and Public Health (NCDC) and the U.S. Centers for Disease Control (CDC) undertook a two year study on the mortality of women of reproductive age in Georgia after finding evidence of large disparities between national reproductive health survey data and official estimates of abortion rates. The 2008 Reproductive Age Mortality Study (RAMOS) investigated the deaths of all women ages 15-49, residing in Georgia who died in 2006. Although initially limited to causes of maternal mortality, it was expanded to include all causes of death for this population and found cancer to be the leading cause of death, and breast cancer the leading single cause of death. The study found significant underreporting of cancer deaths by 25%, over-reporting of circulatory system disease deaths by 190% and ill-defined symptoms by 61% (Serbanescu, 2009). These findings indicate a need for additional research on cancer in Georgia.

In 2008, the City of Tbilisi together with United Nations Population Fund (UNFPA) launched a reproductive health cancer screening program offering free screening to women in the target population (40-70). In 2011 the federal government began replicating it in several regions across the country. The National Screening Center (NSC) has been instrumental in increasing access to free screening (mammography and ultrasound) among the target population. Still, screening continues to be viewed as a diagnostic tool rather than a preventive tool. The 2011 UNFPA Standard Progress Report found that 13,912 women were screened in 2011, or 55% of the target population and concluded that the “National Program should put very intensive efforts to increase the screening program participation rate.” (UNFPA, 2012) As cited by Harford

(2011), WHO suggests that screening coverage under 70% is unlikely to have a significant impact on mortality. It is evident that the provision of free screening alone is not enough to convince women to utilize the service. Püschel (2009) reported similar findings in a qualitative study of women in Chile which improved "understanding of the specific factors behind the evidence that shows that the availability of free mammograms is not enough to increase screening rates in the population."

Research Question and Objective

This study explores how beliefs, knowledge, understanding of the illness, cultural norms, coping strategies, resources, and social support influence how women in Georgia experience breast cancer from detection through treatment to identify barriers and facilitators that shape illness management and survivorship.

Literature Review

A review of online databases including PubMED, CINAHL Plus and IARC on breast cancer and Georgia returned fewer than 10 articles, all of which were quantitative and dealt with medical treatments and one on mistakes in treatment dosage, but not one qualitative publication. An expanded search using "Russia" returned only qualitative articles on breast cancer among Russian immigrants and "Ukraine" returned two on breast cancer survivors in Ukraine (Bishop, 2001; Doan, 2001). A search using "Eastern Europe" returned one article on barriers to cervical cancer screening in Serbia. A broader search not limited to the post-socialist region produced several qualitative and mixed methods studies exploring the lived experience of breast cancer among women in Lebanon (Doumit, 2010), Brazil (da Costa Vargens, 2007), Chile (Püschel, 2010), Finland and Sweden (Arman, 2002), Greece (Almyraidi, 2011), Norway (Landmark, 2001), Ethiopia (Dye, 2011) and Turkey (Cebeci, in print). Other studies examined the experiences of immigrants and minorities including Latina and Hispanic Americans (Luquis, 2006; Florez, 2009; Livaudais, 2010), African Americans (Hall, 2008; Sheppard, 2010), Arab Americans (Obeidat, 2011), Native Americans (Daley, 2012), Samoan Americans (Tanjasiri, 2011) and Russians in Israel (Remennick, 2003) and Russians and other minorities in Kazakhstan (Chukmaitov, 2008) and Canada (Paisley, 2002). These articles explore a wide range of issues including: knowledge, stigma, copying styles, body image, living with loss, fatalism, destiny, faith, fear, patient-provider relations, patient participation in treatment decision-making, individual action and survivorship. Still, no qualitative studies on this topic were found for Georgia and while several of the themes in the literature emerged repeatedly across multiple studies in other countries, the way in which women internalized, expressed or dealt with them differed, highlighting the importance of examining the Georgian experience to better understand both the barriers and facilitators for breast cancer care among women in Georgia.

METHODS

Study Design

Given the lack of research on living with breast cancer in Georgia, a qualitative research approach utilizing semi-structured individual interviews and one focus group were used to explore the patient experience of managing breast cancer. Thematic analysis of the translated and transcribed narratives was conducted to identify and qualify common themes and patterns expressed across the narratives (Sandelowski, 2003).

Appropriate efforts were taken in this study to meet ethical standards and maintain participant confidentiality. Institutional Review Board approval was granted by the University of Washington and the NCDC. All participants received and signed a consent form before each interview or focus group and all names have been replaced by pseudonyms to preserve anonymity. Interviews were digitally recorded with the consent of the participant. Participants were offered tea and given a necklace as a thank you for participation.

Setting

All data was collected in Tbilisi, Georgia in July 2011. Cancer is not openly discussed in Georgia so it was necessary to establish rapport and explain that the motivation for this study was both to fulfill a degree requirement, but also to highlight the experiences and concerns of breast cancer patients and survivors. The researcher was mindful of each participant's understanding of her condition and mental state, initially using terms such as "breast health", "breast illness" and "inflammation of the milk ducts" instead of "breast cancer" in speaking with participants. All participants were aware that they had breast cancer, and while some used the Russian or Georgian term, others preferred "tumor". The investigator is not Georgian, but lived there for four years and is familiar with Georgian traditions, social, cultural and gender norms.

Local organizations active in breast cancer awareness were supportive of this project and cooperated with the researcher to carry out the study, they are: Women Wellness Care Alliance “HERA”, the National Screening Center (NSC) and the National Cancer Center of Georgia (NCC). HERA is a Georgian non-governmental organization based in Kutaisi raising awareness about breast cancer in Georgia through events such as the Race for the Cure, media and training workshops. HERA began raising awareness about breast cancer in 2006 with its first Walk to Save Lives in Kutaisi. In 2009, the organization moved the event to Tbilisi and received official Susan G. Komen sponsorship and permission to use its trademarked Race for the Cure name. The event attracts around 2,000 people annually to a park overlooking the city where walkers circle a small lake on a pedestrian path. While there is press coverage and the event is supported by First Lady Sandra Roelofs, the event is held out of the way of the general public and relatively few survivors attend. Those survivors who do attend are seated in a designated covered area and do not participate in the walk. The NSC, founded in 2008 by the City of Tbilisi and UNFPA under the patronage of the First Lady, conducts breast and cervical cancer screening in Tbilisi. The 400-bed NCC, founded in 1977, provides prevention and early detection, treatment for cancer (surgery, radiation, and chemotherapy), outpatient services, and palliative care as well as conducting clinical trials and managing the national cancer registry.

Sampling

Flyers regarding the study were made available at the July 2, 2011 Race for the Cure in Tbilisi. With the assistance of two students from Tbilisi State Medical University, contact information was collected from 33 women at the event interested in participating in the study. Volunteers were then contacted by phone to arrange interviews. Of the 33 initial volunteers 14 participated in in-depth interviews and 12 participated in the focus group (for scheduling purposes). Three of the 33 could not be reached for follow-up; 2 left the capital to visit their villages in the regions (common in the summer months) and were unavailable for interviews; one did not meet the guidelines presented below (diagnosed in 2005); and one did not feel well enough to participate. Additional participants were recruited from the NCC with approval of the center's director. The researcher spent three days visiting the NCC where four eligible patients were approached and all agreed to participate. Participants met the following criteria: 1) diagnosed with breast cancer between January 2008 and January 2011; 2) diagnosed with stages I, II, or III; 3) willingness to be interviewed in Russian or English, or Georgian with a native speaker present; and 4) over 30.

Data Collection

Qualitative data was collected through semi-structured interviews and one focus group (see Appendix A). Basic demographic information was collected from all participants. Based on participant preference, interviews were conducted in a private office in central Tbilisi (13), a restaurant (2), at the NCC (3) and a participant's office (1). Fifteen interviews were conducted in Russian, two in English and two in Georgian. Interviews ranged from 30 to 90 minutes. At the end of July a focus group was held with 12 additional women recruited from the original list of names collected at the Race for the Cure and through the NSC. The focus group was held at the NSC during nonoperational hours. The focus group was moderated by the researcher and audio-recorded. Questions were asked in Russian by the researcher who is proficient in Russian and familiar with Georgian. Focus group participants spoke both Georgian and Russian interchangeably. The focus group provided an opportunity for gaining additional perspective and confirmation of preliminary concepts and themes through dialogue and group discussion, as it is through this exchange and dialogue that greater understanding is brought to events and experiences (Crooks, 1991). Informational interviews were conducted with four healthcare providers, five professionals (program management, nonprofit and donor agencies) and one city official. These interviews were not part of the qualitative study, but shed light on the situation in Georgia regarding breast cancer and helped the researcher to gather background information and support in locating demographic data on the breast cancer population in Georgia. Sampling from this population was purposive and based on knowledge of the issue and professional involvement. Data was collected by the researcher in Georgian, Russian and English and transcribed in English. Russian transcripts were translated and transcribed by the researcher and reviewed by a native speaker. Georgian language transcripts were translated and transcribed by a research assistant who is a native speaker.

Data Analysis

The translated and transcribed transcriptions were entered into Atlas.ti 6.2 for coding and thematic content analysis (Corbin and Strauss, 2008; Bernard and Ryan, 2010) by the researcher. The coded transcripts were reviewed for common or key concepts and themes as well major patterns that arose in patient narratives and compared across the narratives using the constant comparison method in an attempt to describe the women’s lived experience managing breast cancer (Markovic, 2006). Illustrative quotes from the narratives are included in the results.

RESULTS

Narrative and demographic data was collected from a total of 31 women (19 in-depth interviews and 12 focus group participants). Participant age at diagnosis ranged from 34 to 68 with both a median and mean of 53 years of age. The sample represented education attainment from secondary through university (educational attainment is generally high in Georgia due to the Soviet legacy) with variation in profession and socio-economic status (see Table 1). Analysis of the data revealed three major factors influencing women's experiences and perceptions of living with breast cancer in Georgia: beliefs, awareness and resources. These factors are used as categories to illustrate both barriers to detection and treatment as well as facilitators for survival. Barriers to detection and treatment were expressed in terms of fear, denial and disbelief while facilitators for survival were expressed in terms of faith, dignity and agency (see Figure 1).

Table 1: Study Participants with Breast Cancer

Age at Diagnosis		Interview (19)	Focus Group (12)
	30-39	2	0
	40-49	7	4
	50-59	4	7
	60-69	6	1
Stage at Diagnosis			
	I	6	2
	II	8	7
	III	5	3
Marital status			
	Married	9	6
	Never	3	2
	Divorced	2	1
	Widowed	5	3
Children			
	0	5	1
	1-2	13	10
	3+	1	1
Education			
	Secondary	4	4
	University (+)	15	8

Barriers to Detection and Treatment

Beliefs: Cancer as a death sentence

Participants acknowledged that prior to diagnosis they viewed cancer as a death sentence and were, for the most part, not aware of survivors. "I had such a belief that if you get cancer you will die. This was my experience because my sister died…" said Salome. Such life experiences contributed to denial and a fear of knowing. This fear of learning of a positive diagnosis was reinforced by a lack of awareness regarding survivorship and resulted in a delay in diagnosis for some participants, as indicated by Nana, "I do not know [why I waited]…I think that I was afraid and did not want to find out about it. Before, I did not even know anyone who had it." Despite seeing cancer as a death sentence, the fear of learning of a positive diagnosis did not imply a fear of death, but a fear of cancer. Participants were more accepting of death than illness. They were not afraid of dying, but afraid of knowing, as illustrates by Ana, "they found something in this breast…they said don't worry, I felt so bad and I didn't go anymore. I didn't want to know." And while this perception of cancer as a death sentence was highly prevalent for participants prior to diagnosis, views changed, albeit for some more quickly than others, as they met with health care providers, thought about their family, and met other survivors (discussed below as a facilitating factor). This view of cancer as a death sentence is perpetuated by the lack of awareness and knowledge regarding survivorship and persists as a barrier to screening and detection.

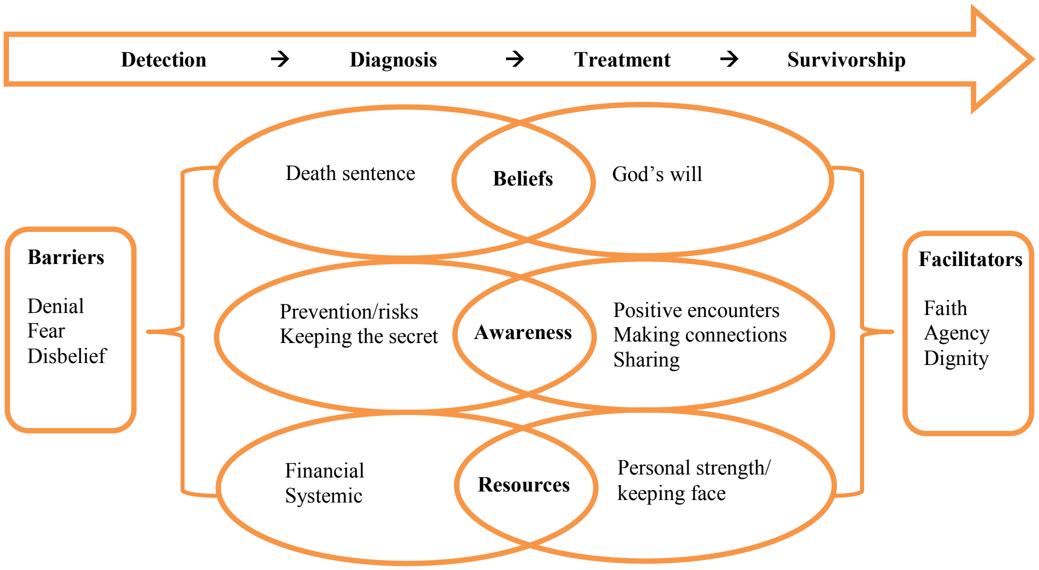

Figure 1: Diagram of Findings

Awareness: Prevention and risk-factors

The proliferation of misinformation and general lack of awareness and disbelief regarding breast cancer is reflected in the disregard for preventive measures and screening. Ninety-five percent of participants only presented for screening upon detecting a lump and only one participant practiced regular breast self-exams (BSE) and screening prior to diagnosis. Susana responded to the screening advertisement, but only after finding a lump, “When I found the lump, in two days I saw the advertisement on the television. I saw the advertisement earlier, but I thought there was no reason.” Participants were also unaware of the risk factors for breast cancer, but speculated it could be caused by trauma to the breast or stress. In 2008, Nana was in a car accident, “my family tells me that my sickness is because of that, they say it is because I hit my chest…I think maybe it’s due to stress.” While some participants expressed disbelief upon detection or diagnosis because they had no family history and believed it was only hereditary, others with a family history of the illness were dismayed by the odds of it striking a family more than once, as indicated by Salome:

> *I didn’t believe. I didn’t believe at all. I didn’t think it. My sister died from this and I thought for me it would pass... I thought it couldn’t be possible that one sister would get it and the second just the same.*

Women simply did not believe they would ever get breast cancer and saw no need or value in preventive measures. Even when aware of the free screening programs and encouraged to participate, women disregarded secondary prevention because they did not understand it. Again, this denial and disbelief is rooted in limited knowledge of breast cancer risk factors and prevention.

Awareness: Keeping the secret

Secrecy, or a lack of disclosure for the purpose of protecting the patient or family members, or due to a feeling of shame, appeared repeatedly throughout the narratives and was practiced by both providers and patients. Despite fear of a positive diagnosis and living with cancer, once faced with a positive diagnosis, women expressed a strong desire to be told the truth by their provider and to be informed of their condition and treatment. But participants did not always trust that they would be provided with this information, as expressed by Diana:

> *They called me and said, 'you have cancer and you must hurry and come back for analysis.' I went along and I went by myself. When you go with someone else they tell them [the diagnosis], they don't tell you straight.*

Patient suspicion is not unfounded. Providers admitted that they do not always tell the patient their true diagnosis, explaining that they determine what the patient is capable of handling. The additional uncertainty of not knowing the truth about one's diagnosis increases stress for some patients, "I was so suspicious if my sister was talking with the doctors without me. I wanted to know everything and one day I fought with her…. I was afraid they would hide something from me," admits Ana. Participants also hid their condition from family members and often pursued treatment alone without informing or discussing it with family members or friends. The lack of discourse also fosters a sense of shame among women diagnosed with breast cancer further contributing to the cycle of limited awareness. This was discovered by Ana:

> *You know…people in Georgia do not talk about this. No. Women they are ashamed to say this, at a certain age. Maybe when you are 60 years old they are more comfortable, but young women up to 40s, they still try to hide this.*

Resources: Financial barriers

The most common barrier to care articulated by the participants was a lack of financial resources. Even women fortunate to have health insurance (25% of the population is covered by public insurance; an additional 7% are enrolled in private, corporate insurance schemes) (WHO, 2011), were often unable to complete their full treatment as insurance covers only surgery, not additional treatments such as chemotherapy, radiation, hormonal therapy or other drugs and targeted treatment. Under the newly privatized health care system, private health insurance plans cover doctor consultations, emergency hospital services and some surgeries, but not medicines (except those provided by health care facilities) (UNDP, 2008). For some, this barrier resulted in delayed diagnosis, as was the case for Diana: “I thought I should go to the doctor, I should go to the doctor and go sooner. But, the biggest problem in Georgia is money, it is money. You must find the money.” In other cases women found funds from family members or through selling property to cover partial treatment, but abandoned treatment when funds dried up, as in Salome’s case: “I did chemo. After the operation I was supposed to do more, but it is too expensive and I could not do it. And Herceptin® I could not do that.” This was confirmed by a medical provider who estimated that less than 25% of her patients completed the prescribed treatment.

Resources: Systemic challenges

Tako was critical of what she sees as a dysfunctional system that is failing its patients, expecting patients to manage their own treatment process with insufficient information:

> *Doctors know that they have really illiterate patients, illiterate in terms of this field. They know that, nonetheless they entirely trust those patients to be running their own healing process. If they forget, it is their fault… You are supposed to call them [doctors], ‘tomorrow will be 3 weeks can I come in? There is no structure and that’s one of the reasons why so many people die.*

Observation at the NCC confirmed this situation. Doctors and nurses administering chemotherapy and trastuzumab (Herceptin®) did not know from day to day how many patients would show up for treatment. Patients generally called early in the day to ask if treatment was available or not. Questioned about their treatment, many patients admitted that they did not know how long it would continue and did not have a specific treatment plan. While this did not seem to be viewed as a problem by the majority of patients, this could be due to acceptance of the paternalistic patient-provider relationship or simply not knowing any other method of care. Further, it was evident that patients had extremely limited information regarding their diagnosis, long-term treatment plans, how to manage side effects, prognosis or personal care after treatment. Either way, the burden of managing treatment is placed on a poorly informed patient leaving considerable room for patients to slip through or discontinue treatment. Still, there is a desire to better understand the illness and the process, as Susana expressed: “There is very little information. If only there were books in Georgian, it would be good, about my illness, about the process.”

Facilitators for Survivorship

Beliefs: God’s will

The majority of participants expressed a belief in fate and God’s will with regard to their diagnosis; however, this tendency toward fatalism did not imply helplessness and was not at odds with one’s ability to alter this perceived destiny through human agency (Florez, 2009; Obeidat, 2011). Although participants did not speak about human agency directly, but a need to take action, it encompasses a number of behaviors to which they attributed their beliefs and decisions from detection through treatment. While participant reaction to the diagnosis ranged from stoic to shock and despair, those expressing the latter eventually came to terms with their diagnosis, often seeing it as fate or God’s will and just another of life’s challenges to be overcome. “It is not right to think ‘for what reason did I get this?’ Simply it is God’s will, most likely it is a test, or… he knows why he sent it,” expressed Irina. Participants viewed being a "believer" and following the doctor's orders as requirements for overcoming this "test". They asked little of their providers, reassuring the researcher that they did whatever the doctor prescribed, "I am very obedient. When doctors tell me I do it," said Sarah. Participants overwhelmingly placed their faith in God and trust in their provider to make all decisions regarding treatment. Asked if she found information from any source other than her doctor, Tamriko responded in a reassuring manner: "No, nothing, never. That is what the doctor said and I didn't look for anything else. Later when they gave me a booklet at the screening center, I read that, but until then I did not know anything." Mistrust of providers was only expressed among the younger and most educated participants who opted to seek diagnostic services and treatment outside Georgia.

The decision to seek treatment was also motivated by a responsibility to care for others, but not a fear of one's own mortality, as described by Irina:

> *I knew for a long time that we come into this life and at some point we pass on...I started to think I would not do the operation…but the stress of the diagnosis weighs heavier on one's children. I saw how it was stressful for them, because they started to worry, to try to convince me to do an operation, not to delay, and they won me over.*

The opposite of human agency, viewed as fatalism or passiveness was used in reference to women who did not seek treatment; such individuals were viewed as foolish. Tako recalled how her cousin faced breast cancer:

> *my cousin was a very passive person, you really had to pull her through and nobody will, luckily I was there for her, but if I was not there, nobody would be like, come on now, let's go see the doctor.*

While taking an active role in one's treatment is considered necessary, the perceived active role was limited to listening to one's doctor, in effect transferring God's will into the hands of their provider. While two patients selected more radical treatments than suggested by their physician, the majority put their trust fully in the hands of the doctor choosing to take no role in decision-making. This practice again suggests the existence of a paternalistic patient-provider relationship.

Awareness: Positive Encounters

Throughout their narratives women alluded to positive encounters or actions that helped propel them forward toward survivorship. These episodes served as facilitators, restoring a sense of dignity for the women and helping them cope with their situation. Participants overwhelmingly expressed a positive opinion of their experience with the screening center and their decisions about care were often influenced by this relationship and how they were treated. They repeatedly remarked on the quick turnaround time of test results which gave them a sense of being valued and cared for, as Irina recalled:

> *You know, we did what they suggested at the screening center, because after finding out the diagnosis they called and later they checked back to track the outcome. You have the feeling that you matter to them.*

Meeting other survivors also served as a positive and reinforcing encounter encouraging women to believe in survivorship and find comfort in their condition.

Awareness: Making Connections and Overcoming Survivor Isolation

Living with breast cancer was an isolating and lonely experience for participants, but the importance of connecting with other women proved highly enlightening. Diana remarked about the feeling of not being alone and the profound transformation resulting from sharing: "first of all I met women, I was not alone, there were 20 or 30 women with me…and we talked with one another…and when it ended every woman was a completely different woman." For Susana, connecting with other survivors and witnessing their treatment changed her views on the possibility of surviving:

> *Earlier, you know how I thought, I thought that whoever had this illness, it was over, and probably everyone dies. And now, after I got sick and I see how people do chemo and I think, my views have changed.*

Unfortunately opportunities for connecting with other survivors are extremely limited, under supported and not widely known and are therefore fail to reach beyond a small group of survivors. Ana, who speaks English, turned to the internet to find this sense of community and camaraderie:

> *When I see on the internet these small things… a special bra, or a special swimming suit… you feel like you are not alone, But nothing like this here. That is why women are so shamed and they try to hide this.*

Awareness: Desire to help and share knowledge

Getting to survivorship had a profound impact on how the women viewed the illness and left many with a strong desire to share their experiences with other women. But without a survivor network or existing mechanism through which to do this women find themselves working independently to spread the word in a piecemeal manner. Ana:

> *I can help someone to pass this problem to support someone, but I do not know people who need this. It is very important when you tell someone 'you are not dying, it is not the end of the world, you can live with this. Just follow the doctor's advice.'*

Salome shared this sentiment:

> *You must create a group for those who have had this operation so they have somewhere to go after the operation and hear from others 'I also did that, you don't need to worry, everything will be ok, it will be ok.' You must hold them up.*

Resources: Personal Strength/Keeping Face

In addition to being treated with respect, the women spoke of persevering; of moving forward with strength and hope; and leaving the illness behind. It was important not to dwell on the illness or question why one got breast cancer. Taking action and persevering was viewed by many as a necessity to survival, and the alternative is shameful, as expressed by Irina, "You must live. It is shameful to talk of depression. That is life." Tamriko faced the illness with a very mater-of-fact attitude, alluding to the futileness of questioning why: "I didn't even ask 'why is this happening?' It was just as if it were a tooth." Participants also emphasized the importance of keeping up a strong appearance and shunning pity, as Laila states: "[The neighbors] know, but they don't pity me. You must be strong and everything will be ok."

Summary of Findings

Based on analysis of the data, the experiences, perceptions and breast health care-seeking behavior of women living with breast cancer in Georgia are shaped by their beliefs, awareness and resources. These factors are informed by themes that emerged from the data divided into barriers: fear, disbelief and denial and facilitators: faith, dignity and agency.

DISCUSSION

This exploratory study sheds light on the experiences and perceptions of women living with breast cancer in Georgia illustrating that limited knowledge, awareness and information impacts women's beliefs, attitudes and actions from prevention through survivorship. However, the process of diagnosis, treatment and survival significantly changes participants' views of the illness in great part due to the increased awareness gained through the experience and the realization that it is survivable. Finding other survivors is a key factor in overcoming emotional and psychological stress as well as facilitating recovery and changing beliefs and attitudes about the disease.

The prevailing belief that breast cancer is a death sentence remains a deterrent to preventive screening. This belief is accompanied by denial and a fear of learning of a positive diagnosis. Hall (2008) and Mayo (2001) explored this theme among African-American and rural elderly women in the United States finding an association between this view and socioeconomic status, knowledge of cancer and negative perceptions of the health care system. In Georgia; however, this belief was voiced across ages and socioeconomic groups by predominantly urban women who expressed considerable trust in the health care system. According to the findings of this study, in Georgia this belief is fueled by a lack of knowledge of cancer, specifically risk factors and benefits of prevention, and reinforced by the secrecy around the illness and lack of visibility of survivors. Meeting other survivors and learning survival is possible acted as a facilitator for many participants. This awareness is cited by Harford (2011) as an "upward spiral, leading to even more awareness, more advocacy and more survivors, who then themselves become advocates."

Participants were generally unaware of BSE and overwhelmingly believed, prior to diagnosis, that mammograms are only useful once a lump is detected. This attitude toward mammograms has also been investigated by Püschel (2009) among women in Chile. Like the Chilean study, this study sheds light on women's attitudes toward mammograms and supports the evidence that free screening alone is not a sufficient incentive to increase utilization of screening services (Püschel, 2009). Again this reflects the general lack of awareness and gap in educating women about the benefits of early detection screening methods.

The belief that a diagnosis of breast cancer is God's will further complicates efforts to promote prevention practices and awareness of risk factors. While the causes of breast cancer are not fully understood, there are factors associated with increased risk such as aging, family history, lack of exercise, being overweight, drinking alcohol, late age at first menstruation, never giving birth and not breast feeding (CDC). More than half of the women in the study breast fed for less than 3 months or not at all. Reduced breast feeding has been associated with a higher risk for breast cancer (Porter, 2008). While not all of these factors are modifiable, knowledge of the benefits of established preventive behaviors could benefit women in the future.

While there was a general lack of awareness regarding risk factors and prevention and a strong tendency to attribute a breast cancer diagnosis to God's will, this did not prevent women from taking action and seeking treatment. Like the Dominican women in the study by Florez (2009), God's will was not at odds with the patient's own will to change. Here the notion of agency, defined as the 'will to change' by Florez, and of persevering through being a "believer" and seeking medical treatment complement one another in moving the participant past the illness.

Contrary to Freeman’s (1989) findings that individuals from lower socioeconomic groups place less trust in the health care system than the more affluent, this study found the greatest mistrust of the health care system among participants who were more affluent, younger, internationally connected and English-speaking. Only two participants sought a second opinion or visited more than one doctor and only three participants sought additional information from a source other than their provider. There was no indication that the economically disadvantaged participants are avoiding preventive screening and treatment due to mistrust, but rather due to a lack of awareness regarding the value of preventive measures and financial barriers. Limited financial resources were a general deterrent to accessing the health care system due to the cost of visiting and treatment as well as perceived necessary additional payments. In general participants regularly avoided seeing medical providers due to a lack of financial resources. Once diagnosed, several participants cut their treatment short or discontinued prescribed medications due to a lack of financial resources.

The issue of secrecy is related to both the perceived shame associated with breast cancer and the belief that the patient or family member is not strong enough to cope with a cancer diagnosis. While this belief may persist with health care providers and family members, patients expressed the desire to be treated with dignity and told the truth regarding their diagnosis. Overall patients knew very little about their illness other than their stage and did not seek additional information beyond what was provided by their doctor. Even when they did know their stage, it is unclear if they were given accurate information. After interviewing three patients who reported they were being treated for stage II breast cancer, the researcher was informed by the provider that they were in fact stage III and IV. This culture of secrecy combined with paternalistic provider-patient relationship serves as a barrier to the flow of information and awareness of the illness and survivorship. It perpetuates the status quo, stunting community mobilization around health issues, resulting in an underdeveloped demand for institutional development for patient rights (Chanturidze, 2009).

The importance of connecting and sharing experiences with other women living with breast cancer was instrumental in restoring a sense of dignity and overcoming isolation. These connections were viewed as life-changing and instrumental in their survival. This also involved witnessing others' experiences with treatment, making comparisons and realizing one is not alone and in fact there are others who had been through more difficult treatments.

Limitations

The limited sample size used in this study may not be representative of the full spectrum of breast cancer patients in Georgia as it was dominated by women who had either previous awareness of the organization HERA, the National Screening Center, attended the Race for the Cure or were willing to discuss their experiences with breast cancer. The experiences of women who do not feel comfortable discussing their illness and women living in remote areas were not represented. In addition, the women who participated in this study are breast cancer survivors and their knowledge, beliefs, attitudes and experiences may differ from those of women who did not survive breast cancer. Their knowledge and beliefs also differ from women in Georgia without breast cancer. This is exploratory research and the first of its kind in Georgia. The intent was to identify common experiences that might indicate areas for future research or common barriers and facilitators that may be experienced by others in their own way. While translation can impact interpretation of interview data, the information collected was not linguistically sensitive.

Recommendations

The findings of this study illustrate that from prevention through survivorship, women in Georgia stand to benefit from improved knowledge and awareness of breast cancer risks and treatment as well as mechanisms through which to share their experiences and find physical and emotional support. As the government of Georgia expands screening programs across the country in an effort to downstage breast cancer diagnoses, it must recognize that increasing access to free screening alone is not sufficient motivation to increase screening. Given the financial concerns and limited resources of the population it would be worth highlighting the financial benefits of early diagnosis and treatment vs. later stage diagnosis which often results in limited treatment options and cost-prohibitive radiation and chemotherapy. Still, increased mammography screening alone cannot reduce overall mortality and has its own risks such as inconclusive results, human error, false positives, over diagnosis and cost (Sulik, 2011).

Efforts to expand access to mammography and ultrasound screening should also be accompanied by a multi-faceted information campaign addressing risk factors and the benefits, both health of secondary prevention through screening. Educating women about the risk factors for breast cancer may encourage more women to respond to public service announcements and participate in screening. It would also be useful to include this information on the NSC website. Existing information stresses the importance of screening, but fails to educate women about risk factors. Training has been conducted for primary health care providers on educating patients about breast cancer programs; however, the effectiveness of these efforts are unknown as 95.8% of the general population often avoid visiting a physician, turning to self-medication instead (Collins, 2003). Pharmacies are abundant and highly frequented in Georgia, making them a potential supplier of information regarding breast health awareness. According to a client satisfaction survey conducted by the NSC, 98% of women surveyed would recommend the screening center to friends and family (UNFPA, 2011); however, this resource is not being utilized. The increased emphasis on screening and risk factors should also be accompanied by greater awareness of modifiable health behaviors, for example educating younger women about the benefits of breast feeding.

At the diagnosis and treatment stage, patients indicate that they prefer to be told the truth about their diagnosis and treated with dignity and respect. While participants stated that were generally pleased with their providers, they wanted more information but also recognized that the providers were overburdened and did not see it as the doctor's duty to provide this information. Still, they did not know where to seek information and support and continued to view the doctor as the only reliable source of information. While some information is available through the screening center, it would benefit patients to make it more readily available at treatment sites as well. Providers should also be informed about patient rights and the value they attach to being treated with dignity and respect, which includes being told the truth about their diagnosis and condition. Past provider training programs have focused on the clinical and managerial aspects of screening programs and the role of primary care in screening programs, but they have not addressed the concerns of patients. Bringing survivors and providers together in future training programs to better educate providers about the concerns and needs of their patients as well as their desire to be informed of their diagnosis and provided with information could help survivors prepare for and address the side effects of treatment.

The survivorship aspect of cancer remains seriously underdeveloped and underappreciated, yet has the potential to benefit many women. Breast cancer survivors in Georgia have indicated a desire to share their experiences in an effort to educate other women about survivorship and provide support to women with breast cancer, yet they remain in the shadows of current efforts. These women would benefit from advocacy training to advance survivorship awareness and barriers to care. The Breast Cancer Advocacy Toolkit developed by this researcher is a free resource designed to help women identify their strengths and commitment comfort level. It also provides guidance on identifying stakeholders, message development and donor cultivation. A more visible role and public presence in society for breast cancer survivors is instrumental in demonstrating that the illness is survivable. Increasing efforts to reach out to younger survivors should also be pursued.

Conclusion

This study helps to shed light on the barriers and facilitators to screening, diagnosis and treatment of breast cancer in Georgia through examining the experiences and perceptions of women living with breast cancer. Improved understanding of these factors can help providers, policy makers and public health professionals target their efforts to increase screening participation and down stage breast cancer diagnosis in Georgia. The findings from this study support the need for establishing survivor networks for breast cancer patients, developing educational materials for patients and their families, informing providers of patient perspectives, concerns and needs and educating policy makers about challenges in accessing care. These efforts would benefit greatly from involving breast cancer survivors in a more visible and active manner.

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APPENDIX A: Semi-Structured Interview Questions

Name
Date of Birth
Marital status
Number of Children (gender and ages)
Age at first birth
Birth weight (participant birth weight)
Time with a parent (early life)
Length of time participant breastfed her children
Education completed
Place of work
Date of diagnosis
Stage at diagnosis

1) Tell me how you came to find out about HERA?
2) I would like to hear your story about being diagnosed with this illness; tell me how you knew something was not right?
    a. How did you feel?
    b. What did you do? Why?
    c. What did you understand to be the best thing to do?
3) What information do you have about your condition?
4) Where is this information from?
5) How would you describe this illness/tumor/breast cancer?
6) What did you think about breast cancer before you were diagnosed?
7) How have your thoughts changed?
8) Tell me, how has your life changed since you found out you had breast cancer?
    a. Socially
    b. Physically
    c. Emotionally
9) What lead to these changes?
10) What was your first meeting with a provider like? Did you go back?
11) What has been your experience meeting with providers since then?
12) How would you describe your treatment?
    a. What are the biggest challenges?
    b. How is it covered?
13) Are there aspects of your life history that you think might have affected your health and breast cancer?
14) Talk about your feelings for the future and how you think breast cancer will impact your life?

Questions for Providers, Professionals and Officials:
Name
Profession
Years working on breast cancer issues
1) Please explain your professional connection to breast cancer (what work do you do?)
2) What can you tell me about how breast cancer is viewed/addressed in Georgia? (by your profession?)
3) What can you tell me about your work and goals related to breast cancer?
4) What challenges to do you face?
5) What do you see as priorities in addressing women’s health and breast cancer?